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ABSTRACT

In 1982, Protection and Advocacy, Inc. (PAI) was awarded funds to provide advocacy services to Hispanic and Asian developmentally disabled persons residing in California. Initial target populations selected were the urban Korean, Vietnamese, and Hispanic communities of Los Angeles. The project's goals were (1) to provide training in self-advocacy skills; (2) to increase availability and accessibility of services; and (3) to insure attainment of services through advocacy for human, civil, service, and legal rights. The acculturation process of California's Asian and Hispanic groups is encumbered by language, family, and religion. But each subgroup has its own reasons for being reluctant or unable to discuss problems or seek assistance. Buddhist-influenced groups, for instance, feel enormous guilt over disabled family members. For many Hispanics, social services bear the stigma of "charity," and undocumented Hispanics must avoid any attention. PAI had to develop a methodology that addressed these characteristics--and one that educated culturally insensitive providers. To reach target groups, PAI undertook an extensive media campaign. It led training workshops for consumers and providers, translated a manual on California programs for the disabled, and produced information brochures in Spanish, Vietnamese, and Korean. Two types of advocacy were provided: short-term assistance and direct representation. The project has managed to narrow the California access "gap," but one of many continuing problems is the lack of knowledge displayed by many service providers regarding their responsibility to provide equal and accessible services to minority communities. After the termination of grant funds, PAI will be institutionalized. (KH)

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FINAL REPORT

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PROJECT OF NATIONAL SIGNIFICANCE FOR PROVIDING ADVOCACY SERVICES TO HISPANIC AND ASIAN DEVELOPMENTALLY DISABLED PERSONS RESIDING IN CALIFORNIA

Grant No. 90DD0025/01

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INTRODUCTION

The California protection and advocacy system, Protection and Advocacy, Inc. (PAI), was established in 1978. Consistent with the mandate of the Developmental Disabilities Assistance and Bill of Rights Act, PAI was designated to advocate for and protect the rights of developmentally disabled Californians.

In 1982, PAI was awarded a grant for $100,000 from the Office of Human Development Services (OHDS) and the Administration on Developmental Disabilities (ADD) for a Project of National Significance to provide advocacy services to Hispanic and Asian developmentally disabled persons residing in California. Initial target populations selected were the urban Korean, Vietnamese, and Hispanic communities of Los Angeles.

GOALS AND OBJECTIVES

Goals for the project centered around insuring that Asian and Hispanic individuals with developmental disabilities had equal access to appropriate services in the least restrictive environment. Goals were:

1. To provide training to developmentally disabled persons and their families in target Asian and Hispanic communities in order to improve self-advocacy skills so that they would understand and influence, to the maximum extent possible, those systems which directly affect their lives.

2. To further the availability and accessibility of services to minority developmentally disabled individuals and to insure that they are afforded the same opportunities and quality of life as other citizens.

3. To insure that Asians and Hispanics with disabilities receive appropriate services within the least restrictive environment through advocacy designed to protect and enforce their human, civil, service and legal rights.

Objectives for achieving these goals fell within three broad categories: Outreach, Direct Advocacy Services, and Training and Information Dissemination. This report summarizes accomplishments and relevant data generated by project activities and analyzes the project's impact.

SELECTED SERVICE TARGET GROUPS

In order to understand problems encountered during the term of the project, including the barriers to services and the strategies employed, it is important to understand the basic target populations, as the unique needs of these groups dictated the project's design.

California has the largest ethnic minority population of any mainland state. 1980 census figures reflect that over one third of California's population is composed of ethnic minorities. Hispanics comprise 19.2 percent of California's population (4,544,366) and Asians represent 5.3 percent of the population (1,254,433). Thus these two groups account for nearly a quarter of California's total population. Further, since California serves as port of entry for thousands of newly arriving immigrants, refugees and undocumented persons, it is estimated that by 1990, 63 percent of Californian's population will be ethnic groups, with minorities then comprising a majority of the state's population.

While Regional Census Data reported the significant size of these minority communities, it did not provide more integral information about the culture, values, educational background and other sociological characteristics which had to be taken into consideration in developing an effective advocacy project.

The Asian Community

There has been a tremendous increase in the number of Asian immigrants to this country in the last ten years, particularly Vietnamese, Laotian, Cambodian and Korean populations. Sparse attention has been given to the specific needs of these communities and thus few understand the concept of service delivery. There is an even greater lack of understanding of the concept of advocacy, service rights and due process and procedural safeguards.

The Korean Community

The Korean population is one of the fastest growing of these immigrant groups. Approximately 30,000 Koreans per year immigrate to this country, and the majority permanently reside in the Los Angeles area. Community sources estimate the Korean population to be as high as 250,000 in Los Angeles, Orange, Ventura and San Bernardino counties. In the United States, the Korean community has grown from 70,000 in 1970 to an estimated 574,000 today. Although Korean communities also have grown up in New York, Chicago, Houston and elsewhere, the Los Angeles area has, according to Ki Byung Yoon, Director of the Korean Cultural

Service in Los Angeles, "the greatest population of Koreans outside the Orient." Koreatown has its own Korean telephone directories, three banks, one savings and loan, more than 120 Korean schools, which maintain Korean language and culture among children, five art galleries featuring Korean works, two symphony orchestras and 430 churches.

Even so, Koreans are little known to the general public. A principal reason for this, according to Eui Young Yu, Korean-American Professor and Chairman of Sociology at California State University, Los Angeles, is that Koreans do not form ethnic neighborhoods, as Italians or Poles did in the early stages of their American immigration. "The Korean community is non-territorial, (and) based on associations," Yu says.

Most Koreans are recent immigrants with an average length of residence in the country of about five years. They find the ways of the Western world very new, making the acculturation process very slow, as they still subscribe to their native culture. There is a small percentage of Koreans who speak English well enough to be understood, but the vast majority are monolingual with no English skills at all. This language barrier is continually reinforced because they, for the most part, are a closed society which provides very limited opportunities to hear the English language. Not only linguistically isolated, Korean people have nothing in their background which enables them to understand the concept of "service delivery". Accordingly, they underutilize existing social services. This unfamiliarity in conjunction with cultural characteristics impedes their involvement in the developmental disabilities and advocacy movement. While the information and outreach among many other ethnic minority groups has certainly not been adequate in many respects, there has, by and large, been more effort directed toward those groups who are more visible than has been directed towards the Korean population.

Compounding these problems is the lack of qualified Korean interpreters and professionals in Los Angeles who are trained and knowledgeable in the developmental disabilities and social services fields. Because of their short U.S. residency, these new immigrants find the technical language unfamiliar and difficult to interpret without assistance. This absence of Korean interpreters results in a lack of materials written in Korean, as well as culturally inappropriate assessment instruments, limited rehabilitation and habilitation programs.

A significant factor to be considered when providing advocacy services in the Korean community are views concerning the traditional family unit. Korean culture dictates that the family unit is the most important institution with the father playing the dominant role. While the family is being challenged by such factors as the economic necessity of women working outside the home, the family unit still remains an important consideration. More significant is the attitude toward disabled

family members. Traditionally, Koreans believe that a disabled child has brought shame to the family. As a result there is an unwillingness to discuss the child with others and a strong tendency to attempt to resolve the problem within the family rather than to seek outside assistance and benefits. This combination of language and conservative attitudes toward the disabled creates a significant barrier to obtaining services for disabled family members.

The Indochinese Rufugee Community

Indochinese refugees share with other Asians a formality in relationship. In all relationships, the elder or the person of superior status is accorded respect, even though he or she may be a stranger. Thus it is difficult for the Indochinese to challenge bureaucratic decisions. Further, most refugees are raised to avoid direct communications. In other words, what Americans might call nonresponsiveness may be the Indochinese refugee's very subtle way of saying "no". If an Indochinese refugee does not keep an appointment, or if he does not follow through on a plan, it does not mean that he is irresponsible. Instead, he may be communicating that he does not feel capable of doing what is requested.

As with other Asians, Indochinese refugees have enormous guilt feelings over having a disabled member in the family. Due to the influence of Buddhism, many believe that they did something wrong during their previous life and are being punished in this life. Therefore the Indochinese are reluctant to discuss their problems or to seek assistance.

The Hispanic Community

Hispanics are the largest immigrant group admitted to this country. Within the last five years, it has been estimated that 490,000 Central Americans have permanently settled in California. Further, given Los Angeles County's proximity to the Mexican border, many Mexican workers add to the rising numbers of new immigrants. While there are a number of unifying qualities such as language, strong sense of family and strong religious convictions, each of the subgroups that comprise the Latino population has unique cultural attributes which pose barriers to obtaining services and which must be considered when developing an advocacy service model.

Some Hispanics living in California are from families that have lived here for two or three generations. They are English speaking and are basically acculturated to the American way of life. In fact, many of this group have no sense of belonging to other cultures, cannot speak their native languages and feel alienated from their parents. A significant number of this group have graduated from high school and some have semi-skilled jobs.

This group generally has knowledge of the various service systems. However, this knowledge is not the equivalent to use of the service system or the development of advocacy skills that will assist them in obtaining benefits. Rather, receiving benefits is viewed as receiving charity. They are hesitant to ask for services for their children because they are proud and do not want to be labeled as "welfare" precipients. This group connotes accepting Medi-Cal or Supplemental Security Income for a developmentally disabled child with not being able to provide for that child, discounting the inordinate financial burden often resulting from the needs of developmentally disabled children.

Another sizeable and growing portion of the Hispanic community is the new wave of immigrants, refugees and undocumented persons. This segment of the community has needs which are different from those Hispanics who have lived in this country for several generations. Most of the recent immigrants are monolingual. Further, many within this group are campensinos (farm workers) from Central America or Mexico with limited educations. As a result, some cannot read or write in Spanish.

Many of the new immigrants are "undocumented" and this label colors every aspect of their life, including their relationships to their employers, the educational system, and the system of financial entitlements or government benefits. Because their status is so precarious, many are quiet and docile, and avoid drawing attention to themselves. This docility leads them to not question those in authority, not to demand any services, and indeed not to learn what services are available, including services available to their American citizen children. Further, the whole idea of a system of benefits and services is foreign to them. As a result of their undocumented status, limited ability to speak English and lack of formal education, this group is in the lowest economic stratum, further compounding their plight.

Traditional values and religious convictions are also a significant consideration within this group. Within the Latino community, it is clearly the mother who bears the entire burden of the developmentally disabled child. Frequently, even when the father is still in the home, the mother alone feels the emotional, physical, and psychological strain of caring for such a child. The problems of this community are also compounded by the fact that there is frequent denial of a child's disabilities. Parents and relatives of disabled children pray to God, make journeys to shrines, whatever it takes to "cure" the child. Many times, mothers will across the boarder to Tijuana, Mexico to see doctors for their children, both because they trust them and because they do not have medical insurance or Medi-Cal coverage.

It is within this group that the most violations of rights take place. The parents are intimidated by a system they don't understand. They don't speak the language of service providers and very often those agencies do not provide interpreters.

They are not knowledgeable about services their children may need, and if they are, they are too intimidated to ask.

Many are turned away because they're often told erroneously that being undocumented precludes the delivery of services to them. These violations of law are also a function of service providers' awareness of this populations's timidity and the fact that they will not object or protest if services are denied or reduced.

METHODOLOGIES FOR ADDRESSING THE UNIQUE NEEDS OF THE TARGET COMMUNITIES

In order to develop an effective advocacy project, it was necessary to develop strategies which addressed the unique characteristics of the target communities. Particular areas addressed were language, unfamiliarity with the service system, lack of service providers who were members of target communities or who were bilingual, and lack of service provider personnel sensitive to the cultural patterns of the target communities.

Language was and continues to be the primary barrier for most recent immigrants. Steps were taken to insure that PAI was accessible to non-English speaking clients. Bilingual, bicultural advocates were hired to work with the Hispanic and Asian communities. (The Hispanic advocate was an attorney, the Korean advocate held an M.S.W. degree and the Vietnamese case aide was a trained paralegal). In addition, the project hired a bilingual (English/Spanish) secretary and continued the practice of utilizing an answering machine recording in Korean, Spanish and English, in order to insure access to advocacy services when the bilingual staff was not available. A toll-free hot line was also established so that members of the minority community living outside the Los Angeles area could have access to bilingual, bicultural staff. In addition, PAI hired translators when necessary to accommodate clients who spoke languages other than those spoken by PAI staff.

While the hiring of bilingual, bicultural staff was viewed as essential to the success of the project, some difficulty was encountered in the hiring process. For example, while PAI was able to hire a Spanish-speaking attorney and secretary, the selection processes proved more difficult than anticipated in that most applicants did not meet the requirements for the position, which included bilingual and bicultural requirements as well as familiarity with the developmental disabilities service system.

It was also necessary to address the language barriers which existed in service agencies. Most written material regarding rights and entitlements of the developmentally disabled as well as formal agency notices are in English. Project staff addressed these barriers through trainings and materials development.

Parents and consumers were alerted to the lack of native language materials, provided with information about relevant laws requiring provision of materials in native languages, and assisted in developing strategies on how to effectively address language barriers. Trainings were also provided to service providers regarding their legal obligations to make services accessible. Further, in that so little material was available in native languages, and more importantly, in a form understandable to populations with a limited education, PAI developed a training manual on service rights and entitlements. The manual addressed the critical need for knowledge of basic rights, service entitlements, and included tips for successful advocacy.

Another major problem was the lack of culturally responsive and appropriate service models. Current service systems have emerged primarily from the advocacy efforts of middle and/or upper class Caucasian families. These persons are adept at working through and with bureaucracies. The service systems, as a result, reflect mainstream values and presumptions about experience and skills in accessing bureaucratic systems. Service providers, at best, are ignorant of relevant cultural and subcultural differences and dynamics, and, at worst, hostile to those who require special accommodation, support and assistance in accessing services and systems.

The impersonal style of intake procedures of many agencies offends and alienates many minority persons seeking services. PAI addressed this barrier by training service providers about the unique cultural factors of the clients they serve. Many of the subjective cultural factors previously noted were crucial to understanding minority groups. For example, among the Korean and Hispanic populations, there is the very strong sense of "family" and the mother is seen as one who dedicates her life to her children. It is most inappropriate, for example, for service providers to presume out-of-home placement when supportive services in the home would be much more acceptable to family values.

Project staff also addressed the many cultural and legal factors which inhibit requests for services from service agencies and had the potential to inhibit requests for advocacy assistance from PAI. The undocumented status of many Hispanics with the accompanying docility and lack of advocacy skills was a significant barrier to services. This was addressed in a variety of ways, including the establishment of a project advisory committee, involvement of staff in community activities, provision of direct representation and the teaching of advocacy skills.

PROJECT ACCOMPLISHMENTS

Project accomplishments fell within four broad categories: Outreach, Training, Direct Representation and Information Dissemination. In each of these project areas, it was necessary to

develop strategies which would take into account the previously described cultural and language factors of the target population. The strategies developed by project staff and accomplishments in each area are discussed below.

Outreach

A critical component in the project was outreach or the development of contacts and visibility within the target community. Due to cultural factors, the target populations were hesitant to discuss problems with, or to seek assistance from, individuals who were not members of the community. Further, PAI had limited contact and visibility within the target communities. Thus the outreach strategy focused on developing trust and a presence in the target communities.

A critical element in the project was reaching those target community families with developmentally disabled members who were effectively excluded from service systems. These were persons who had not been linked to the service delivery system in any meaningful way. An outreach method, which supplemented distribution of brochures and media presentations, was utilized that was culturally responsive to community preference for a more personalized approach. Referral points included community leaders as well as respected organizations within the target communities, religious leaders, social workers, health personnel, etc. These individuals and agencies were provided with information about services and advocacy resources so that they could be called upon to assist in linking potential clients.

Selected individuals were invited to serve on a project advisory committee. This committee was not only important to the project's credibility, but was also an important source of expertise to staff, as some committee members had years of experience in the developmental disabilities field. Moreover, the committee members served as liasons between the project and the community and thus as sources of referral. They were essential to developing rapport with target communities. The members included community leaders, professionals, and parents of developmentally disabled individuals.

Visibility was gained by undertaking an extensive media "blitz" which let the community know of the project's existence. News releases in Korean and Spanish describing the project's services were aired. Over 200 news releases were sent to service providers, government agencies, parent groups and professionals. Project staff also made appearances on television talk shows. Moreover, project staff were interviewed and articles were printed in the major newspapers serving the Latino and Asian communities. La Opinion, the most prominent and widely read Spanish newspaper in the Los Angeles area ran an extensive article on the project. Similarly, the Korean Street Journal, the leading Korean community newspaper published an article.

Articles were also printed in local Chinese, Vietnamese and Cambodian newspapers.

In addition to the extensive media campaign, PAI staff identified existing parent groups representing minority developmentally disabled persons. The two leading, most visible and influential groups were the Korean Parent Group and the "Concilio", the State Hispanic Developmental Disabilities Council. Staff attended their meetings and spoke about the project objectives and discussed methods for obtaining referrals and strategies for serving clients.

Presentations also were made to community organizations serving the target populations, such as churches and social service agencies. These presentations were designed to provide these agencies with information about the project as well as to solicit endorsement of the project, identify needs of the target community, as well as key community leaders and to solicit referrals.

Brochures describing services available through PAI were translated into Spanish, Korean, Vietnamese and Cambodian. Dissemination of the brochures was a priority of the outreach process, as it was a simple and effective means of providing the community with information which could be retained and referred to later. In total, over 11,000 brochures were distributed to the Korean, Vietnamese, Cambodian and Latino communities.

An ongoing aspect of the project's "trust building" and contact with the community was staff members' visibility in the community. Staff could not be seen as separate and distinct from the community served, but as a part of the community. As a result, staff members attended community meetings unrelated to disability issues.

Training Activities

Training workshops were the primary mode utilized to inform developmentally disabled consumers and service providers of the legal rights and service entitlements afforded developmentally disabled individuals. Staff provided training to 345 primary and secondary consumers and 30 providers.

In conducting the trainings, it was necessary to be cognizant of and sensitive to a number of dynamics which affected the location and content of the training sessions. All trainings were provided in locations that were readily accessible to the communities involved, both in terms of public transportation and also in terms of physical locations which were important to the community. For example, as religion holds an important place in the target communities, many community meetings took place in church auditoriums. Moreover, most, of not all of the families of the targeted populations were working class people. In order

to accommodate to their working schedules, PAI staff provided most trainings on weekends and during evening hours. More importantly, the trainings were provided in the native language of the groups served.

It was also important to structure the content of the trainings to the needs of the community groups. In addition to dealing with subjects such as special education, Social Security and Medi-Cal; staff addressed more basic concerns in the trainings, such as whether an undocumented youngster was entitled to special education, how to ask for an interpreter and how to address the "machismo" syndrome -- the father's unwillingness in many Latino families to become an active participant in the developmentally disabled child's life.

One of the most significant project goals was the development of a comprehensive training manual that set forth the legal rights and service entitlements of developmentally disabled persons. Very few native-language materials were available at the beginning of the project period. If the project was to have any lasting impact in the community, it was considered essential that basic training manuals be developed which described the service systems. This goal was accomplished during the third quarter of 1983, with the development and translation of Service Rights and Entitlement Programs Affecting Developmentally Disabled Californians. The manual provided information on each service system that impacts developmentally disabled persons, as well as advocacy tips to insure that consumers would be able to utilize the substantiative material.

Development and translation of the manual proved to be a significant challenge for staff. While staff recognized the importance of providing consumers with complete information, it was also important not to overwhelm the reader with material which was too technical. This concern was addressed in a number of ways, including making each service system an independent section of the manual which could be used separately, providing the information in a question-and-answer format so that the reader could have the option of reading the entire section or manual or skimming to obtain an answer to specific questions, and providing lists of applicable laws and regulations so consumers could obtain additional information should that become necessary. In order to address concerns that the manuals would become outdated, the manual was placed in a spiral binder to which updates could be added. Staff has retained names and addresses of consumers so that they can be sent copies of updates.

Translating the manual into Spanish, Korean and Vietnamese also proved to be a challenge, as numerous words did not have a direct equivalent in the other languages. For example, in English the title of the manual is Service Rights and Entitlement Programs Affecting Developmentally Disabled Californians, however, since there is no direct translation in Spanish or Korean for the word entitlement, the Korean and Spanish titles deleted the word.

Additional problems were encountered with the Spanish translation in that the translated materials were reviewed by three Hispanic individuals all from different countries at origin. Each translator suggested a different appropriate translation. There were also class issues that impacted on the Spanish translations. In particular, the translation had to strike a median between the very formal and proper Spanish and a less formal Spanish which would be understandable to someone with a very limited educational background as well as an attempt to develop a "generic" translation useable by people from different countries of origin.

Direct Representation

A significant portion of the project's activities focused on representation of individual clients. Two types of advocacy services were provided: short-term assistance and direct representation. Short-term assistance occurred on a daily basis and included the provision of basic information concerning rights and entitlements and, when appropriate, referral to community resources. Direct representation of an individual included activities such as attendance at an IEP meeting or representation at an administrative hearing. Statistical data reported on the following chart reflects the problem areas in which assistance was provided.

	NUMBER OF ASIAN CLIENTS Short-term and Technical Assistance/Direct Advocacy	NUMBER OF HISPANIC CLIENTS Short-term and Technical Assistance/Direct Advocacy
EDUCATION		
Assessment	0	2
Eligibility	6	1
IEP Development	5	7
Related Services	5	7
Placement (Public School)	2	4
Placement (Nonpublic School)	0	7
Due Process Procedures	0	2
Complaint Procedures	1	2
Other	2	7
FINANCIAL ENTITLEMENTS		
SSI Eligibility	40	5
SSI Overpayments	5	4
SSI (Other)	5	7
SSA Benefits (Child Benefits, SSDI)	1	1
Medi-Cal Eligibility	4	4
CCS Eligibility	10	1
CCS Share of Cost	3	1
IHSS Eligibility	10	0
IHSS Share of Cost and Other Financial Liability	0	1
IHSS Number of Hours	1	1
Other Program Eligibility	4	0
Other Program Share of Cost Or Financial Liability	1	0
Other	0	4
HABILITATION SERVICES		
Eligibility (WIC 4512(a))	12	3
IPP Development	6	1
IPP Implementation (coordination, purchase, advocacy, development of services in IPP)	2	3
Complaint or Hearing Procedures	0	4
Residential Placement	3	7
Special Residential Services (WIC 4681(c))	2	0
Vocation/Rehabilitation Services	15	1
MEDICAL TREATMENT		
Medi-Cal Services	13	2
CCS Services	8	0
Regional Center/Medical Treatment	5	3
Other	1	1
MISCELLANEOUS		
Abuse/Neglect/Exploitation	0	1
Criminal Justice Issues	1	2
Guardianship/Conservatorship	0	6
Housing	13	1
Mental Health Services	2	2
Residency	0	1
Return to Community from Institution	0	1
Rights in Institution	0	1
Right to Treatment/Refuse Treatment	1	0
Other	6	32
TOTAL	195	140

Advocacy services provided by project staff differed from the usual PAI agency case load both in the type of case as well as the type of advocacy assistance provided. While the case load touched upon all service areas - education, regional center disability, Social Security, Medi-Cal -- the problems presented concerned much more basic access questions and required more support and time per case. The frequency with which such basic access questions arose clearly underscored the failure of the service system to provide minority communities with equal access to services.

The target communities faced "first-generation", initial access and disability problems. Mainstream communities, by way of contrast, tend to have "second-generation" advocacy issues needs -- related not so much to access, but toward achieving "quality or appropriateness." Further, mainstream families often have some degree of experience or bureaucratic sophistication so that they are better equipped to act as self-advocates than are families in the target communities. The needs differential between mainstream and target community families translates to more "hands-on" support services needed and cases necessarily become more time consuming. This must be recognized and recommodated in designing culturally appropriate service models.

Clients of the project were much more reticent to challenge recommendations made by service providers. They would request hearings to challenge provider action only with the encouragement of both project staff and other respected members of their communities.

Cultural and language factors also contributed to the type of advocacy issues encountered by staff. Many providers assumed that since staff members were bilingual, they would satisfy the provider's need for translation services. Staff instead spent a significant portion of their time enforcing the service agency's obligation to provide interpreters.

Because of ethnic community cultural patterns fostering a reluctance to assert rights or disagree with identified authority figures, cultural support groups played important roles in assisting target community families in overcoming barriers to equal access to service and resources. The project relied heavily on these groups and organizations within both the Hispanic and Asian communities and would have met with much less, if any success without them.

Support groups provide a point of entry for newly identified families with developmentally disabled members. These groups can assist family members in moving beyond the stigma which may be associated with a developmentally disabled family member, toward effective accessing of services from providers. Such support activities become arenas for self-advocacy. By working with newer members or members in crisis, other members gain confidence and advocacy skills. A support group is also a means for

disseminating information about the rewards of successful advocacy. Success in one member's case gives courage to others in asserting their rights. The groups also provide a means for airing and resolving grievances with provider agencies, grievances that would be difficult to raise in an individual case. The groups are also a means for compelling service provider responsiveness to the cultural patterns and needs of ethnic minorities.

To be maximally effective, however, support groups should not be created by providers. It is imperative that such groups are independent in order to insure the group is free to make its own decisions or from their own views and style. Where there is no extant support group, then a priority would be fostering the development of such a group -- i.e., as an outgrowth of a training session where follow-up is done collectively or by supporting those persons in the community seeking to pursue a course of action collectively.

Project Materials and Information Dissemination

The project proposal called for dissemination of project information and materials in order to stimulate replication. Significant materials developed during the project have been widely distributed, both throughout California as well as nationally. The Washington, D.C. (central office) and Region IX Office of the Administration of Developmental Disabilities (ADD) have assisted both in identifying target organizations and individuals and in the distribution of materials.

In addition to English, information brochures describing the project were printed in Korean, Spanish, Vietnamese, and Cambodian. A training manual, Service Rights and Entitlement Programs Affecting Developmentally Disabled Californians which is described elsewhere in this report, was the major product developed in the project. Over 3,000 manuals were printed and distributed to individuals, groups, and organizations during the project period. Project staff compiled the names and addresses of organizations and community leaders throughout the target communities within California. Manuals were sent to each of these individuals and organizations with advance permission to duplicate and distribute them to members of their organizations and others. In addition, the manuals were used in the trainings conducted by project staff within the minority communities. Finally, the central (Washington) office of ADD arranged to have materials printed and distributed to all existing protection and advocacy organizations in the states and territories.

In order to continue distribution of the manuals after the expiration of the project, a $4.00 voluntary contribution has been requested to cover printing and mailing costs for those who can afford to pay. Demand to date for the manuals has far

exceeded the expectations of project staff, probably due to the lack of other materials available in targeted languages.

In addition to the distribution of the materials, presentations were made by the project director to share project information and findings. These included a presentation at the National Association of Protection and Advocacy Systems (NAPAS) in Washington D.C. in May of 1983. This meeting included staff and board members of protection and advocacy agencies throughout the country, as well as representatives from other developmental disability groups and organizations. A second presentation was made in October of 1983 in Kansas City. This four-state developmental disability conference was sponsored by Missouri Advocacy Services. The conference included representatives from the states of Missouri, Kansas, Iowa, and Nebraska as well as those from ADD Region VIII. The conference was designed as an information and educational forum to present information and discuss the needs of minority populations within the four-state area as well as to develop strategies to address those needs by service agencies. The project director had the opportunity to share project information and materials and to participate in discussions with those present regarding ways in which their organizations might improve service delivery to these special populations. According to the final report prepared by the coveners of the four-state conference, "agency staff now has the strategies to pursue services to minority populations in future activity." An action plan was developed at the conference in order to pursue service development to target populations in the four state area.

Plans were finalized for an additional presentation to be held after the close of the project period at the ADD Regional Forum West. The meeting was held February 28 March 2, 1984, in Aurora, Colorado, and over 300 persons attended. Participants included, in addition to protection and advocacy agencies, staff and members of state developmental disabilities councils, university affiliated programs, state legislators, state administrators, vocational rehabilitation agency staff, program providers, parents of persons with developmental disabilities, primary consumers with disabilities, and volunteers as well as related Health and Human Services staff roam the western and midwestern states. The project director was able to spend time during the the conference providing consultation and technical assistance to individuals attending regarding replication ideas within their specific organizations and/or states and territories.

This final project report will be distributed throughout California, and with the assistance of ADD, to the protection and advocacy agencies in other states and to other elements of the federal developmental disabilities program.

PROJECT IMPACT

Changes within the Target Groups

Most significantly, due to project trainings, the targeted communities exhibit a heightened awareness of the protections afforded to developmentally disabled persons, including an understanding of the right to certain services of a particular quality and quantity. As direct result of these efforts and because of peer and community support, the target groups' members' willingness to pursue advocacy activities hearings was greatly increased by the final weeks of the project.

Although these advocacy efforts were successful, much remains to be done. At a recent conference held in the Bay Area for Spanish-speaking developmentally disabled persons and their families, a state level administrative hearing officer noted that Hispanic individuals accounted for only 2 or 3 percent of all requests for administrative hearings, while the percentage of California school-age children who are Hispanic is obviously many times greater.

A major source of the positive change noted within the community can be attributed to the publication and dissemination of PAI's Service Rights and Entitlement training manual. As more manuals are used in the communities, they will heighten the awareness of the community members regarding basic rights to services and will increase understanding of the service delivery system. Dissemination of this manual is viewed as the project's most significant accomplishment, as the manual will continue to assist the community after the project. PAI receives requests almost daily either for copies of the manual or for permission to reproduce it.

Changes with Service Providers

Although some changes have occurred within the service system as a result of the trainings provided by staff on such topics as: providers' obligations under Section 504 and Title VI; minority communities continue to encounter many problems. For example, an obvious and consistent lack of knowledge is displayed by many service providers regarding their responsibility to provide equal and accessible services to minority communities. Too many service providers either are not aware of, or simply ignore, their legal obligations. Equally critical is the general lack of outreach to these communities by service providers and health and human service agencies. Further, many cultural differences and insensitivities continue to plague and hamper the delivery of service to the minority community. Many service agencies continue to offer services only in English even when they have linguistically appropriate staff working in another unit. Similarly, providers continue to be insensitive to cultural docility, the needs of undocumented

persons, and the importance of family. These continued abuses unequivocally underscore the continued need for advocacy projects in the minority community.

While this project has narrowed the access gap somewhat in California, a "Grand Canyon" of a gap remains because of the size of the target communities and their degree of isolation from the mainstream. As long as there are culturally isolated ethnic communities, equal access will require an allocation of outreach and advocacy resources beyond what would be needed by comparably-sized mainstream communities. Ongoing allocation of supplemental resources, including service resources, may be necessary to preserve family integrity, particularly for the generation in the assimilation process. Without ongoing extra assistance, the stress target community families face during the assimilation process, coupled with the stress of a developmentally disabled family member, may lead to family disintegration, as manifested by the developmentally disabled family member's delinquency or inappropriate out-of-home placement. Equal access by target communities of significant size can be secured only through long-term commitment of extra resouces toward such a goal.

Changes within PAI

The project grant funding provided PAI with the impetus to undertake the development of a culturally and linguistically appropriate service model. With the implementation of the grant came changes within the grantee agency itself, due to a growing understanding and awareness of the needs and problems facing members of the target minority communities.

Rather than abandon the work begun, the organization has instead chosen to institutionalize the project after the termination of grant funds, i.e., the project's objectives have been internalized and integrated and staff have been hired as permanent members of the organization. While there is much more that PAI can and should do to provide services to minority communities, this voluntary project outcome clearly demonstrates how a relatively small amount of grant funding can serve as the catalyst to propel an organization into a desirable direction of change in meeting the changing demographics of its service population.